



**PREPARED COMMENTS FOR THE
HIT POLICY COMMITTEE
MEANINGFUL USE WORKGROUP**

USING HIT TO ELIMINATE DISPARITIES: A FOCUS ON SOLUTIONS

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Using HIT to Eliminate Disparities: A focus on Solutions

FollowMe was one of the first of the 1st Generation Personal Health Records (PHRs) when it went live in 2000. Over the past 10 years we have upgraded and customized the FollowMe platform for additional special populations with a focus on people who face challenges in the healthcare marketplace as a result of culture, language, socioeconomic or health status. Of these, I would like to discuss MiVIA, a PHR initially developed for migrant and seasonal workers, and our most notable in terms of serving vulnerable populations and having an opportunity to address disparities. The second is Health Shack a PHR launched in January 2010 and developed specifically by and for homeless and system based youth.

Launched in 2003, MiVIA (<http://www.mivia.org>) now serves approximately 24,000 people in six states. It has evolved from an application geared specifically to migrant and seasonal workers to a more expansive application that provides individuals and their families a way to manage their fragmented health information. It also provides an information sharing solution for hospitals and mobile health solutions that care for patients at multiple locations and across health systems.

MiVIA and Health Shack “members” carry a photo ID emergency information card that lists conditions, allergies, and emergency contact information. This card provides a sense of security for these consumers/patients especially when they are confronted with language barriers in an emergency setting.

MiVIA works because we **engaged** the community to help design a PHR to meet their needs. Using focus groups and consumer advisory committees, we continually try to upgrade the PHR to address issues such as condition-specific health information, insurance and coverage issues, worker safety, immunizations, and how to navigate the health care system. Our PHR applications are first and foremost Health Advocacy tools.

Our partners use community outreach workers and *Promotores* (lay workers who come from the community) to explain the PHR to the community. We have thus been able to establish trust between the consumer and their PHR, to learn what features and functions are important, and to upgrade the PHR platform to meet their needs.

Mobile Youth

In 2008, we partnered with UC Davis Dept. of Adolescent Medicine and WIND Youth Services, a youth shelter based in Sacramento, California to determine if MiVIA would be of benefit to homeless youth as well as those aging out of foster care systems. For 18 months we worked with and listened to these youth to understand what they needed and how they used technology in their everyday lives. The outcome of this effort was a customized technology solution that was designed by the youth themselves. With grant funding provided by Sierra Health Foundation and United Health Care <http://www.healthshack.info> was developed and launched in January 2010

Lessons Learned

Our 10 years of experience in working with special populations and Personal Health Records has taught us that:

- It is important to understand what the consumer needs – make no assumptions.
- People do not like to be labeled (example: migrants, homeless, at- risk, vulnerable).
- Build trust through peer to peer outreach before deployment.
- Critical to partner with agencies that speak same language and share/understand same culture as the end user.
- Consumers need to have a sense of ownership and control with assurance of privacy and “consent” over their health information.

Recommendations

- Consumers should have access to language appropriate health information materials in electronic format including audio and video media.
- Individual Patient health data should be made available to patients in a variety of electronic formats including free standing, patient owned untethered Personal Health Records.
- EMR products should be required to export standardized data to the patient’s PHR on request.

Getting to 2013-2015

- Support collaboration and inclusion of Community Based Organizations (CBOs) and agencies that have direct responsibility for under-served populations.
- Invest in Pilot Project Funding to explore best practices (24+ months)
- Promote consumer engagement in HIT by local and state governments by introducing consumers to HIT through culturally appropriate efforts.
- Provide limited (3-5 years) job training funding for community based programs such as Promotores/Health Ambassador/Health Advocate programs in doing peer – to peer outreach and education.
- Focus on usability at consumer end, simplicity and cost effective solutions. *One of the constant complaints we hear from providers trying to adopt EMRs is the amount of time and effort and training it takes.*

Panel Questions

- 1. What do you see as the greatest risks posed by the implementation of HIT in relationship to potentially increasing disparities in health processes and outcomes?**

One size does not fit all. One risk is that as HIT is implemented at the provider level it does not do anything to address whether or not people have access to the information they need. What is scattered on paper will continue to be scattered electronically as high risk groups access different systems of care in multiple ways.

2 What are you, or others with whom you work, doing (or planning to do) to reduce the risk of exacerbating disparities as HIT is implemented across the county?

FollowMe has been developing customized PHR products that are being implemented through partner agencies which work specifically with medically vulnerable populations.¹ Partner agencies are typically resource agencies targeting specific population, i.e. immigrant families, system based youth, developmentally disabled, homeless, as well as condition specific populations. (diabetes, hydrocephalus, congenital heart disease).

The role of the PHR is to engage the patient by providing them with a place to store and share their medical information. We also use the PHR to teach consumers about their rights and roles and responsibilities as patients. Additional assets of the PHR are integrated resource tools to help them identify services available to them. We engage the patients by working with CBOs establishing outreach programs, and peer to peer engagement.

3. What research is being done, or needs to be done, in this area to inform the HIT Policy Committee in trying to establish guidelines that will move providers to implement methods of using HIT to reduce disparities?

In our experience there is very little data available that can support the use of HIT in moving providers to implement HIT methods at the consumer level to reduce health disparities. The feedback we get from providers is that they are already overwhelmed with technology geared towards increasing productivity, demonstrating outcomes and even responding to patient emails. This “technology fatigue” creates disincentives.

We cannot burden the providers with additional requirements. What we need to do is give them the tools and technology to share with their patients. **We need to give them something without requiring more from them.**

We would recommend

- a. Implementation of funded PHR Demonstration Projects with Prospective Evaluation and multiple variations of specific interventions that would be helpful in establishing guidelines.
- b. More pilot project funding linking research partners with community based organizations and local governments.

4. With patient and family engagement in care at the forefront of our thinking about improving our Nation’s health, what particular strategies would you

¹ Vulnerable population – Medically vulnerable for a variety of reasons, including language barriers, literacy, socioeconomic status, insurance coverage, chronic medical conditions.

recommend to us as potential meaningful use requirements in 2013 and 2015 for the vulnerable populations we have asked you to address?

Strategy One: Require EMR products to seamlessly send relevant data from the EMR to the PHR of the patient's choice. This will enable patients to collect and manage information from multiple sources/providers/EMRs and to share that information with relevant parties.

Strategy Two: Provide incentives for providers to offer culturally and language appropriate educational materials through the electronic media of patient choice. (Word documents, video, audio, mobile)

Strategy Three: Provide resources for local and state governments that will **trickle down** to community based organizations to provide out reach and peer to peer training for orientation and enrollment (example need people to educate consumers, do the outreach and enrollment into MiVIA. Provide funding to tie into extension centers for patient engagement and provider support of patient engagement.

Strategy Four: Institutionalize PHR technology by expanding PHR pilots in Medicaid and Medicare populations while simultaneously promoting innovation by providing a choice of "certified" PHR vendors to beneficiaries.

5. How can the meaningful use of HIT specifically reduce a health disparity?

By introducing HIT and engaging patients through connection with local organizations that serve them and building capacity of the organizations they engage with by providing technical assistance.

By customizing consumer tools and PHRs to specific populations addressing the cultural issues and providing information in a non-threatening, non judgmental approach. Deployment of information through mobile tools in the language of choice. Expanded use of video and audio tools.

6. What specific HIT applications have been used to address health literacy

The Health Shack PHR uses video clips to educate its users. We are in the process of developing audio clips on specific conditions and in multiple languages. The Health Shack videos are actually produced by the youth themselves promoting peer-to-peer engagement. On the MiVIA website we have links in Spanish to medical and health information and resources. Both MiVIA and Health Shack Members have a medical information card (tied to the software application) listing emergency contact, conditions, allergies and medications. This card is extremely important to the MiVIA members and the Health Shack members. Our entire PHR websites link to Medline Plus which provides consumer education materials.

Concluding Comments - From passive recipients to active participants

In order for HIT to have meaningful use for consumers and their families personal health data must be able to flow seamlessly and securely from EHRs to PHRs, irrespective of the consumer's location, employment, healthcare providers, or insurer.

We have an unprecedented opportunity as technology, patient empowerment and health reform converge. We also have a great responsibility to protect those most vulnerable.

Meaningful Use in HIT does not simply mean building a patient portal on an EMR system with the ability to download a bunch of forms in different languages at a particular grade level. Meaningful Use as it relates to consumers and especially those who face barriers means the ability to connect patients, clinicians and caregivers to provide, in a respectful manner, **the right information at the right time, in the most appropriate way for the best outcome.** And, to insure that information sharing does not have adverse consequences to the consumer.

In terms of HIT and consumers we need to continually rethink and retool. The solution does not mean slapping a different label on an existing product. EMR systems have evolved from 20 year old legacy Practice Management Systems which were built to increase productivity and enhance revenue of physicians and hospitals in a fee-for- service environment. Today these products have so many bells and whistles that doctors and their staffs need to take classes just to learn how to use them which in itself is creating barriers to adoption.

There are simpler and more cost effective solutions and the innovators should be encouraged and rewarded for developing them. We need to acknowledge that the EMR industry is a billion dollar industry and until a ROI on engaging consumers can be developed the push for meaningful use for consumers will need to come from the policy makers and the payers.

HIT and Meaningful Use as it relates to consumers, especially vulnerable populations, means developing and implementing what some might call disruptive technologies that will result in cost savings to the system as a whole and redirecting funding back to the providers and communities serving these populations while rewarding simplicity.

The FollowMe Vision:

One day soon, I want to log in to my PHR and connect to my different providers at different facilities and request downloads of visits and pertinent information that I can share with my family and caregivers. I want to go to the online library in my PHR and download condition specific modules that will help me manage my medical conditions and those of my family members. I want to be able to watch a video or listen to medical information in the appropriate language by simply clicking a button on my PHR dashboard. I want to locate the most affordable medications at the closest pharmacy and to know what my out of pocket expenses will be if I go to the local hospital for non emergency care. I want a "virtual" medical home to help me navigate an ever changing healthcare landscape.

Thank You.